MHDS Redesign ID/DD Workgroup

Meeting #1
August 23, 2011, 10:00 am to 3:00 pm
United Way Conference Center
1111 9th Street, Des Moines, IA

MINUTES

Attendance

Workgroup Members: Jim Aberg, Ron Askland, Bob Bacon (Co-chair), Mary Dubert, Marsha Edington-Bott, Dawn Francis, Stephanie Gehlhaar, Jan Heidemann, Terry Johnson, Cindy Kaestner, Karalyn Kuhns (Chair), Roger Lusala, Susan Seehase, Dale Todd

Legislative Representation: Dave Heaton, State Representative, House District 91 (Henry County) and House Chair of the Health and Human Services Appropriations Subcommittee; Jack Hatch, State Senator, District 33 (Polk County) and Co-chair of the Legislative Interim Committee on MHDS Redesign

Facilitators: Valerie Bradley and Lilia Teninty, Human Services Research Institute (HRSI)

DHS Staff: Connie Fanselow, Jennifer Harbison, Joanna Schroeder, Ken Tigges, Robyn Wilson, Brian Wines

Other Attendees:

Ronda Bennett	Iowa Department of Inspections and Appeals
Amy Campbell	Polk County Health Services/ID Action
Marcy Davis	Candeo
Mardi Deluhery	Parent
Kyle Frette	Easter Seals Iowa
Zeke Furlong	Iowa Legislature, House Staff
Linda Hinton	Iowa State Association of Counties
Sandy Hurtado-Peters	Iowa Department of Management
Sara Lupkes	Polk County Health Services
Michelle Moore	Harmony House
Ann Riley	Center for Disabilities and Development
Steve Roberts	Disability Rights Iowa
Rik Shannon	Iowa Developmental Disabilities Council
Stuart Simonson	Whittemore, IA
Carol Warren	Progress Industries
Casey Westhoff	The Arc of Iowa
Dion Williams	Systems Unlimited

Agenda

Agenda Topics:

- Introductory Remarks and Workgroup Overview
- Overview of Best Practice in State ID/DD Services Nationally
- Where the Iowa DD System Compares to National and Other State Norms
- Eligibility for Services - Best Practice And Trends In Eligibility Determinations And Standards
- Group Discussion of Key Decision Points
- Next Steps
- Meeting Summary
- Public Comment

WORKGROUP OVERVIEW AND INTRODUCTORY REMARKS

Introductory remarks by Karalyn Kuhns:

Key points of Senate File 525:

Legislature's stated intent is to redesign the system for adult disability services to:

- Shift funding responsibility for the nonfederal share of adult Medicaid disability services from the counties to the State
- Reorganize adult disability services not paid for by Medicaid into a system administered on a regional basis that provides multiple points of access
- Replace legal settlement with residency as the basis for determining financial responsibility
- Meet the needs of consumer in a responsive and cost-effective manner

Redesign Process:

- DHS has convened workgroups to develop recommendations for regionalization, mental health services, intellectual disability services, children's services, brain injury best practices and programs, and involuntary commitment
- The Legislative Interim Committee membership has just been finalized
- Workgroups will provide products and recommendations to the Interim Committee so they can craft legislation
- The Intellectual Disabilities and the Mental Health workgroups have the same set of responsibilities, which include:
    - Eligibility criteria for individuals to be served
    - Identification of an array of core services
    - Identification of outcome and quality assurance measurements
    - Provider accreditation, certification, or licensure requirements
    - Working closely with Medicaid as a key funder of services
    - Adherence to Olmstead principles
    - Implementing mental health crisis response and sub acute level of care
    - Addressing provider and workforce shortages
    - Addressing co-occurring conditions
    - Providing cost estimates

- Workgroups have a big challenge to meet in a short time
- The legislation provides the starting point
- Goal is to get the work products and recommendations back to the Legislators
- Members need to think globally and listen to all points of view
- Balance the ideal with fiscal reality
- It is important for the efforts of all groups to be coordinated as their work is interdependent
- A Coordination Committee will help to monitor and ensure that coordination

Accessing workgroup materials:

- Joanna Schroeder has been hired as a project manager and will coordinate materials
- All meeting documents will be posted on the DHS website
- There is a page for general redesign information
- Each workgroup will have a page where materials for that group will be available
- The DHS website updates daily at 2:30 pm

Public comments may be offered at the end of each workgroup from about 2:45 to 3:15 pm.

Introductory remarks by Bob Bacon:

- Everyone's contribution to this effort is appreciated
- Many people participating have worked on redesign efforts before
- This time there is a firm legislative intent to move forward
- There is more awareness of the Olmstead Decision than ever before
- There seems to be agreement that the 1996 dollar cap for counties cannot continue
- The Technical Assistance Collaborative and Human Services Research Institute are here in Iowa to provide technical assistance
- Working together we can improve Iowa's mental health and disability system for everyone

Introductory remarks by Representative Dave Heaton:

- This is difficult and complex work
- Legislators are still learning from families, consumers, providers, and others
- We are relying on these workgroups to come forward with a plan we can put into place
- Consumers should have equal access across the State
- Reimbursement rates should be level across the State
- Local access is important
- The role of the CPC in local access should not be diminished
- In the past the State has relied on funding partnership with counties

- If the State fully funds, we need to consider how to maintain a partnership with counties to ensure fiscal responsibility
- We have to understand and control costs
- Assessment tools and information provided to case managers must be reliable
- Services funded need to be based on accurate assessment of need
- We must balance the needs of consumers and the resources available

Introductory remarks by Valerie Bradley and Lilia Teninty with HSRI:

- The Human Services Research Institute is collaborating with the Technical Assistance Collaborative (TAC) to provide technical assistance for Iowa's redesign effort
- HRSI is based in Cambridge, Massachusetts and Portland, Oregon
- HSRI has been in existence for 35 years and has worked with virtually every state
- Experience working in Iowa
- Val served as Chair of the President's Commission on Intellectual Disabilities during the Clinton Administration
- HRSI developed and manages National Core Indicator projects
- Have found that every state is different and will share some examples from other states that may fit in Iowa
- Lilia has worked in the states of Illinois and Indiana managing their developmental disability service systems

Meeting 1 Handouts:

- Meeting Agenda
- List of Workgroup Members
- Calendar of Redesign Workgroup Meetings
- Workgroup Meeting Locations
- DHS Redesign Website Directions
- Summary of Senate File 525
- Overview of Nation Trends in State DD Systems and Eligibility Determination
- Data Report: Where Does Iowa Stand?
- Best Practices in Self-Directed Services and Supports
- State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants
- Home and Community Based Services Intellectual Disability Waiver Information Packet

OVERVIEW OF BEST PRACTICE IN STATE ID/DD SERVICES NATIONALLY

Overview of national trends:

- States are being expected to do more with less
- We need to think differently about the delivery of services
- Aging baby boomer population is demanding more long term care supports

- We are part of a virtual community grappling with same issues
- Systems put in place 20 or more years ago based on residential, custodial facilities and sheltered workshops are not sustainable
- A lot of people have been moved out of large institutions
- At the state level, staff reductions have diminished institutional memory and knowledge
- Most states need to figure out how to manage an increasing complex system with a smaller and smaller staff
- CMS (Centers for Medicare and Medicaid Services) has increasingly become a driver of practice for intellectual and developmental disability services
- They are expanding expectations for state performance and quality management
- The U.S. Department of Justice is increasing raising expectations around the Olmstead Decision
- They are taking Olmstead seriously and pursuing enforcement in many states
- There are concerns about increases in Medicaid long term care costs
- Medicaid HCBS (Home and Community Based Services) Waiver funding continues to increase
- HCBS Waiver services have become a mainstay of the system nationally
- The number of people served by HCBS Waivers continue to increase
- Progress has been made toward more integrated and smaller settings
- More than half of people being served nationally are n living in 1 to 3 person settings
- Increased numbers of HCBS Waiver recipients are living with their families
- Families, consumers, and case managers have different expectations
- Significant growth in the number of children diagnosed with Autism Spectrum Disorders
- More children diagnosed with Autism and children identified as ID/DD are coming into schools
- Waiting lists for services are growing in many states
    - Iowa has less of a waiting list problem than many other states
- Medicaid spending is projected to more than double between 2009 and 2017
- State budget shortfalls are in the billions of dollars after the end of federal ARRA (American Recovery and Reinvestment Act) funds
- Future growth of the labor market is not expected to keep pace with need for direct support professionals
- Major changes in CMS oversight of states:
    - Looking to states to show evidence of monitoring its own processes and procedures
    - Focus on states producing evidence based reports to demonstrate that people are being served appropriately, health and safety is being protected and other assurances are met
    - Expect states to develop incident management systems with the ability to track incidents and responses

WHERE IOWA DD SYSTEM COMPARES TO NATIONAL & OTHER STATE NORMS

Data Report: Where Does Iowa Stand?

- Data collection efforts have been going on for years, including the reports compiled by Charlie Lakin, David Braddock, and others
- These have supplied real data to track how states are doing and show policy makers where there is need for reform
- A report prepared by HSRI compared Iowa to other states in the Midwest region and states with similar populations (Missouri, Kansas, Nebraska, Connecticut, Oklahoma, and Oregon)

The group discussed the fact that Iowa is serving more people per capita than comparison states and the national average:

- May be many reasons – not easy to identify
- Know that other states have higher waiting lists
- Spending numbers seem to indicate Iowa is spreading our resources among more people – serving more people but spending less per person than other states

Opportunities:

- We have evidence about what works and what doesn't work
- Concentrate on what works:
    - People living in smaller settings report more choice and less loneliness
    - People living in smaller settings are more involved in their communities
    - People living at home have more friends
    - People who control their own budgets more likely to control other aspects of their lives
- Iowa is already working to phase down large congregate facilities
- Concentrate resources on productive and person centered program models
- Concentrate on programs that give us value for our money and result in positive outcomes for people
- Continually be guided by your values and the needs of people
- Think about new models and new ways of doing things
- Continue to engage stakeholders in the conversation
- Need to be accountable for public money spent

Group Discussion:

- Meet "needs" but recognize that limited resources may not be able to address all "wants"
- In 2005 the Legislature acknowledged over reliance on institutional, congregate care, which helped bring Money Follows the Person to Iowa
- Data may show that we are still over-represented nationally, but we have made progress
- As resources and services become more scarce, the need to make appropriate assessment to allocate funding becomes more important

BEST PRACTICE AND TRENDS IN ELIGIBILITY DETERMINATIONS AND STANDARDS

Overview of best practice in eligibility for services:

Role of eligibility determination:

- Provide a fair and consistent manner to allocate scarce resources
- Ensure access is available to those who meet the requirements
- Screen out those who don't meet the requirements

Trends in the definition of Intellectual Disability:

- Now ID not MR
- Identification of specific sub-groups, syndromes
- Moving away from identification through just an IQ score
- Looking at whole individual, functional skills, abilities and deficits

AAIDD (American Association on Intellectual and Developmental Disabilities) definition includes:

- Intellectual functioning
    - One criterion is IQ testing
- Adaptive behavior
    - Conceptual skills
    - Social skills
    - Practical skills

Developmental Disabilities (DD) Act definition based on functional criteria:

- Severe, chronic disability of person 5 years of age or older
- Occurring before age 22
- Likely to continue indefinitely
- Substantial functional limitations in three or more areas of major life activity:
    - Self-care
    - Receptive and expressive language
    - Learning
    - Mobility
    - Self-direction
    - Capacity for independent living
    - Economic self-sufficiency

Eight states have adopted these federal criteria for eligibility

Approaches to determining eligibility have changed with definition:

- Categorical or diagnosis specific
- Functional based on ability to perform major life tasks
- 47 states use some combination of categorical and functional assessment processes

Trends in eligibility:

- 31 states use a developmental disability concept as opposed to ID only
- 8 states use the federal definition of DD
- The remaining 23 states use state specific definitions often including categories such as ID, autism, cerebral palsy
- Fewer and fewer states use just an IQ assessment

Eligibility criteria for HCBS ID/DD Waiver Services:

- 34% based on MR definition
- 66% based on broader definition
- If many of these individuals do not quality for the HCBS Waiver, they are often coming into the system in other ways such as jail or hospitalization

Eligibility in Federal HCBS services:

- 1915(c) waivers are tied to an ICF/MR institutional level of care
- Individuals must require the level of services provided by an ICF/MR

Iowa Waiver eligibility criteria:

- Financial – Medicaid eligible
- Functional assessment – must meet ICF/MR level of care
- Categorical – have a diagnosis of ID or IQ of 70 or less

Eligibility for state funded services:

- Nationally, non-Medicaid funding is shrinking as states move these funds into the Medicaid program to capture the federal match
- May be less restrictive than HCBS eligibility
- State funding can provide smaller more flexible amounts for services while people are on waiting lists for HCBS wavier services
- State funding can target supports not covered by Medicaid (housing and rental assistance)
- Want consistent eligibility requirements across the state

Key questions for workgroup recommendations:

- What are the Implications of national trends for the Iowa system?
- What information is needed to change current eligibility framework?
- Are there immediate or long term changes that should be made?
- How can we ensure that we have statewide consistency for people entering the system?

GROUP DISCUSSION OF KEY DECISION POINTS

Group Discussion on eligibility for services:

- Iowa has an HCBS habilitation program in the 1915 (i) option that is needs based, not diagnosed based
- The group is interested in data on who is utilizing that service
- It is key that case managers have accurate and complete information to guide consumers to programs
- Consumer should not have to rely on the individual knowledge of a case manager to get access – all should have training and information
- There is a built in inequity in Iowa's Waivers – different waivers offer different service menus and different levels of funding
- Would like to look at needs based assessments for services
- Want to prevent redundancy in programs and services
- Interested in looking at the Supports Intensity Scale (SIS) as a tool
- SIS is probably too comprehensive and time consuming for eligibility determinations, but very useful for individual assessment and service planning
- When Iowa's ID Waiver was created in 1992 the decision was made to limit the definition to ID only (not DD) for the purpose of limiting costs
- There has been must evolution in the definition of MR/ID since that time

Comments from Senator Jack Hatch:

- Wants workgroups to keep in mind that they are not just writing a report
- Legislators are looking to them to provide specific recommendations that can be crafted into legislation for systems change

Group Discussion on Iowa data report:

- HCBS Waiver numbers on page 2 include 2900 people on the Ill and Handicapped Waiver
- High rate of utilization on page 4 chart may be due to Iowa's mandate to serve persons with intellectual disabilities
- Would like to understand the difference between Iowa and other states in the number of people who receive supports in a family home

Services definition in Senate File 525:

- Services and other supports available to a person with mental illness or an intellectual disability or other developmental disability

Group discussion:

- How long does it take for people in need to enter the system?
- What is the need for emergency services and how are we meeting it?
- Are we serving people in other ways?
- Are we failing to serve people who really need services?
- Nationally 40% or more of people with an ID diagnosis also have a mental health diagnosis

- Is there any data why providers aren't moving more toward community based services?
- What would it take to incentivize providers who are offering ICF/MR services to offer or expand their offering of HCBS services?
- We need to look at sheltered workshops and other employment services
- Should we expand the definition of who we serve to anyone who is at risk of institutionalization?
- Look at U.S. Dept. of Justice's expanded definition of institutional settings
- Are there people with DD now being served in ICFs that are not currently eligible for the ID or other waiver?
- The ID waiver is the most comprehensive and provides a greater dollar amount for more intensive level of service than other waivers
- Services and funding levels within waivers vary greatly
- There is a big gap between the cost of waiver services and cost of ICF/MRs
- Has DHS considered the efficiencies of combining the waivers in a single waiver?
- Iowa Code requires that changes in the waivers have legislative approval
- Is now the time for Iowa to look at the related conditions issue?
- Not necessary to create a second waiver for people with DD
- There are ways of phasing in changes over time
- The more funds that are used up providing mandated services, the less money is left for all discretionary services
- Tie discussion of eligibility to resource allocation and the discussion of core services
- What kind of outcomes do we want for individuals and families?
- Might want to look at upcoming changes in DSM-V to inform us about the standardized accepted definitions that are going to be used moving forward
- Services should be needs based
- Based on functional need with a consistent way to assess & diagnostic criteria that open the door to the functional assessment
- Requires a reliable and consistent assessment tool
- It varies between states who administers the assessment
- Some use ICAP as level of care tool
- Necessary to have case managers or others who can administer and update assessments
- Consider a limited annual eligibility determination process
- Can an annual or re-determination process be streamlined?
- Not a good use of time to retest many for IQ, etc. yearly or even every few years when there is no significant change in condition expected or noted
- Some changes are being made to current waiver rule to reflect that

What some other states have done:

- A "supports" waiver for people living with family members, which covers day programs for people who remain in a family home
- Can be used as a cost containment strategy
- Can impose an annual dollar cap

Group Discussion of SIS tool:

- A lot of states are starting to go to the SIS to do planning
- May want a simpler tool to determine eligibility and level of care
- SIS takes 2 to 3 hours
- Involves bringing together the individual and a group of people who know and are close to the individual
- Having input from a group of people helps balance out expectations
- They discuss and reach agreement
- The scoring process is based on that discussion
- Good feedback on validity
- SIS is a strength based assessment
- Requires credentialing to administer
- AAIDD certifies SIS assessors
- Could increase our capacity with that training and certification
- DHS has used some of its Real Choice Systems Change money to train on SIS
- IME is exploring the idea of having a cadre of full time assessors that could be deployed regionally – that is part of the Olmstead plan
- From a provider standpoint it increases our indirect costs – if we want to do that we also need to look at the cost factor and rate structure

Group Discussion on service eligibility (continued):

- Interest in exploring a bigger "funnel" that includes people with functional needs beyond an ID diagnosis
- Involuntary commitments in Iowa are mandated to be paid for; other mental health inpatient and outpatient costs are discretionary
- Need to be aware that we need data and documentation
- How do we serve other disabilities, including people with IQs above ID, but with functional limitations, people on the Autism Spectrum
- County case management and DHS case management may have different interpretations which lead to different results in assessing eligibility
- Different people make different judgments with the same fact situation
- How do you make it consistent?
- Using the same tool and same training would be a start
- How do you ensure you have reliable, well trained, well supervised people making the decisions?
- How can we use technology (Skype, telemedicine, etc.) to enhance consistency and capacity?
- Need to address issues of differences between community based and institutional rate setting

- Differences in rates is part of what limits community capacity
- What does CMS require?
- Look at CMS requirements & DOJ recommendations and guidance
- What is important to add in?
- If we add too much, it becomes impossible to manage and too expensive
- What results in better outcomes for people?
- How do we deal with the natural reluctance of family members and guardians for individuals with ID to move out of institutional settings and live more independently?
- Do we need to look at a continued medical necessity criteria for people who have been long term ICF/MR residents?
- Can we find out more about the characteristics of people on the Ill and Handicapped Waiver?
- What about people with DD served by the counties; what are their characteristics?
- Can we get more information on people served in ICFs?
- What is the DSM-V definition for ID?
- How have other states closed institutions?
- In Iowa, DHS does not have the authority to close an institution; it has to come from the legislature
- Some states with a strong union presence have moved staff out of state institutions with individuals and maintained state run homes
- A big part of the savings of moving people out of institutions is the savings in wages and benefits
- What is and what is not an institution?
- What about people living in long term care facilities that may be a danger to other residents or staff? Is there a more appropriate environment for them?
- A revolving loan fund is being put into place in Iowa to create a setting for people with high behavioral needs
- Co-occurring issues will be dealt with in this group
- We don't always think about co-occurring with ID/DD population; we need to address that
- There is potential for a regional system to better address co-occurring and complex needs
- Concern that there are not co-occurring inpatient treatment programs where people can get treatment for more than one condition at the same time

NEXT STEPS:

Information requested for next meeting:

- Estimate on how changing eligibility definitions would change numbers served
- Ill and Handicapped Waiver – basic info and profile of enrollees
- Data on county funded developmental disability services (COA code 43) – numbers served and what type of services utilized
- County waiting lists – counties and numbers – new waiting lists expected?

- Length of time people stay on waiting lists? Waiver? Counties?
- 1915(i) Waiver – general information and utilization by individuals with autism
- Report on waivers done by Robin Cooper for the Iowa Council on Developmental Disabilities
- Department of Education data on special education students and graduates
- Characteristics of people being served in ICF/MRs
- Characteristics of people being served by HCBS Waivers
- Waiting lists in other states
- Information on support waivers, tiered waivers
- CMS assurances
- Information/better understanding of Supports Intensity Scale (SIS)

NEXT MEETING: September 6, 10 am to 3:15 pm, at United Way Conference Center in Des Moines

Meeting 2 Agenda:

- Best practice and trends re: Performance measures and Quality Management
- Performance Measures and Quality Management key decision points
- Performance Measures and Quality Management workgroup recommendations

- Will plan to have about 30 minutes at start of each meeting to look at new info
- Will post requested information on webpage as it is available
- Members are asked to bring copies of informational materials that they want to share

- Will talk about outcomes you expect for the system of services and for individuals
- What would it take to know if those outcomes are being met
- For next time, review Best Practices in Self-Directed Services and Supports document
- Will share some information from National Core Indicators
- May look at comparison of NCIs and NOMs
- How do compliance and quality differ?
- Look at CMS quality performance outcomes that cross all waivers (six assurances)

MEETING SUMMARY:

Emerging Areas of Consensus:

Eligibility Process should be:

- Simplified and standardized
- More coherent for families
- One process
- LOC determination should be simplified
- Explore broader diagnostic criteria beyond ID
- Look at CMS & DOJ guidelines

PUBLIC COMMENT:

Comment: Counties submit annual reports to DHS that show populations served and characteristics; those reports could be useful to this process. We want to look at system values because they should relate to system outcomes and demonstrate to legislature that money is being well spent.

Comment: There was discussion today about the expansion of the ID waiver and about consolidation of waivers. It might be helpful to look back at the report Robin Cooper did for DHS in 2004 on the consolidation of the waivers; many of the recommendations are still valid.

Comment: As the parent of a daughter with ID born in 1979, I remember when special education was new and that was all we had. I remember the "old" moms who said we should be so grateful, but when we looked at what else we needed, we wanted more. We didn't want the very nice segregated school they had built and they thought we didn't appreciate what they had worked so hard for. Now I am one of the "old" moms and I see parents now who really need whatever help they are getting just to keep their heads above water. Parents do really appreciate the help we receive.

Comment: Iowa is one of a few states where MHIs can turn down people and they end up in corrections. We ought to be looking at that; people with mental illness should not be ending up in our prisons.

For more information:

Handouts and meeting information for each workgroup will be made available at: http://www.dhs.state.ia.us/Partners/MHDSRedesign.html

Website information will be updated regularly and meeting agendas, minutes, and handouts for the six redesign workgroups will be posted there.